Tullo ES, Young TJ, Lee RP.
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***Dementia* (2016)**
DOI: 10.1177/1471301216651981

Medical students' views about person-centred communication in dementia care.

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Abbreviations

Dementia Communication Questionnaire (DCQ)

Dementia Model of Effective Communication (DeMEC)

Person living with dementia (PLWD)

Acknowledgements

We thank Dr Louise Allan and Professor Louise Robinson for their advice, comments and help with review of qualitative data.

Funding

Ellen Tullo is supported by the National Institute for Health Research Newcastle Biomedical Research Centre based at Newcastle Hospitals NHS Foundation Trust and Newcastle University. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health'.

Declaration of conflicting interests

An article reporting early data analysis from the same project, with an emphasis on cross-cultural analysis, has been submitted as a book chapter and is under review.

Abstract

Adopting principles of person-centred communication has been highlighted as one strategy to improve care of people living with dementia (PLWD) in health and social care settings. However, person-centred communication is interpreted and applied variably in different settings and healthcare professionals' attitudes towards communicating with PLWD are under-explored. This study aimed to investigate medical students' views about the applicability of a model of person centred communication - the Dementia Model of Effective Communication (DeMEC) - to clinical practice. Quantitative and qualitative data was collected using questionnaires (n= 531), focus groups (n=21) and interviews (n=10). Students generally endorsed the person-centred approach to communication, but two aspects were highlighted as complex and divisive - the acceptability or otherwise of lying, and of communicating with family in advance of the PLWD. We discuss the nature of these communicative dilemmas, implications for the education and training of medical students, and future directions for research.

Keywords

Person-centered communication, medical student, medical education, Dementia Model of Effective Communication

Introduction

Proficient communication with people living with dementia (PLWD) is recognised to be key component of person-centred care (Brooker, 2004; Edvarsson & Innes, 2010; Kitwood, 1997). However, communicating with PLWD may be challenging for health and social care professionals, and there is evidence that poor communication contributes to inadequate care of PLWD in hospital and community settings (Alzheimer's Society, 2009; Care Quality Commission, 2012; National Audit Office, 2007; Royal College of Psychiatrists, 2011). Education and training for health and social care professionals focussing on appropriate communication with PLWD has been highlighted as an important strategy for improving care of PLWD (Alzheimer's Society, 2009; National Institute for Health and Care Excellence & Social Care Institute for Excellence 2007; Royal College of Psychiatrists 2005, 2011), and research supports a relationship between optimising communication and improving the quality of life of PLWD and their carers (Orange, 1995; Peterson, Berg-Weger, McGillick & Schwartz, 2002; Ryan, Meredith, MacLean & Orange, 1995; Worral & Hickson, 2003).

The notion of person-centred communication, however, has been interpreted and applied variably in different care settings, and education and training for staff may not link to any particular theoretical framework or research evidence about what effective communication with PLWD entails (Young, Manthorp, Howells & Tullo, 2011). Further, the attitudes towards communication and associated learning needs of staff working with PLWD remain under-explored. Therefore, whilst training to improve communication with PLWD is widely advocated, there is a lack of consensus as to what and how to teach. Improving education and training about dementia necessitates becoming better informed about health and social care professionals' attitudes towards dementia care in general, and more specifically to communication and person-centred care.

The aim of this study was to determine the extent to which the principles and practices of person-centred communication, as conceptualised by an existing model - the Dementia Model of Effective Communication (DeMEC: Young & Manthorp, 2009; Young et al., 2011) - relate to the approaches to communication with PLWD of undergraduate medical students. The majority of medical students, whatever career trajectory they eventually follow, will provide care for PLWD upon graduation - as such, they are an important target group for education and training about dementia (Tullo & Allan, 2011). Historically, education about dementia for medical students has concentrated on biomedical fact-based knowledge, rather than including learning outcomes relevant to attitudes and communication skills (Tullo & Gordon 2013). It is unclear to what extent medical students are aware of, or endorse, a person-centred approach to communicating with PLWD, and what their learning needs are. We sought to explore their perceptions of the nature and complexities of communicating with PLWD as doctors in training.

Methods

The study had a mixed methods design, triangulating quantitative questionnaire data with qualitative data from focus groups and interviews.[1]

Participants

Participants were students in years one, three and five at a medical school with UK and Malaysian sites. The school's largest facility is based in the UK, but a smaller facility opened in Malaysia in 2009. UK-based students were either entry-level year-ones, year threes who

[1] An article reporting early data collection from the same project, with an emphasis on cross-cultural analysis, has been submitted as a book chapter and is under review. This article reports on a larger data set and concentrates on areas of uncertainty about applying person-centred communication to the clinical environment.

had completed the first two years of their programme, or year fives who were in the final year of study. At the time of the study, the Malaysian facility did not yet have year 5 students. All participants were either first language English speakers, or had achieved at least band seven in the International English Language Testing System (IELTS, 2012) or an equivalent, indicating 'fully operational command of the language' prior to commencing their training.

Quantitative data collection

As no validated instrument specifically addressing attitudes towards communication with PLWD existed, the authors produced a 'Dementia Communication Questionnaire' (DCQ) - submitted as supplementary material. This consisted of twelve Likert-style questions, each related to an aspect of effective communicative behaviour identified by the "Dementia Model for Effective Communication" (DeMEC), an existing model of person-centred communication derived from empirical data (Young & Manthorp, 2009; Young et al., 2011). Responses to each item were given a numeric score from 1-5, with higher scores reflecting a greater level of agreement with the person-centred communicative approaches advocated by DeMEC. Some items were reverse coded to minimise the risk of acquiescence bias (Oppenheim, 2000).

The content and phrasing of the DCQ statements were reviewed with Malaysian staff during piloting and no problems were reported in terms of comprehending items in the questionnaire. For reasons related to access and students availability, the questionnaire was administered either as a hard copy or electronically, but versions were otherwise identical. Students were approached prior to lectures or seminars and invited to complete the anonymous questionnaire, or emailed with a link to the online version.

Qualitative data collection

First round - focus groups. Students who completed the DCQ questionnaire were invited to submit their contact details to receive further information about attending a focus group to discuss issues arising from the questionnaire. The focus groups were semi-structured; students had access to a copy of the DCQ statements and the focus group moderator used the statements as prompts for discussion. Students were encouraged to discuss in more detail the statements that they found the most interesting or challenging.

Focus-groups were audio-recorded, transcribed and anonymised. A thematic content analysis was then conducted (Braun & Clarke, 2006) - content was initially categorised and divided using the DCQ statements as a priori derived headings, with related subthemes emerging. Initial thematic analysis of communication issues was undertaken independently by two of the authors (ET and TY), and was subsequently reviewed by a third author (RL) to consider consistency in coding and interpretation. Any coding differences were further discussed amongst all three team members until consensus was reached.

Second round - interviews. Early analysis of focus group data highlighted areas of divergent opinion and controversy with regard to principles of person-centred communication. These challenging areas were explored further through one-to-one interviews with students. Interviews were semi-structured and questions were derived using the subthemes from the thematic analysis of previous focus group data. Data analysis occurred iteratively – each interview was independently coded by ET and RL prior to discussion of key themes. The interview schedule was amended as data was collected and discussion of themes progressed. Interpretation of interview data was also discussed with 2 other academic clinicians to review validity of the findings.

Ethics

Students at both sites were advised that completion of the questionnaire was voluntary and anonymous. Students who provided their contact details were emailed further information about taking part in a focus group or interview before confirming whether or not they would like to participate. Written consent was then obtained. Recordings were kept in a secure location and anonymised. The project met the ethical assessment guidelines for the University's School of Education, and approval was confirmed by its Medical Board of Studies.

Results

Quantitative data

A total of 531 questionnaires were collected from the UK and Malaysian sites: 283 were completed by year one students, 114 by year 3 students, and 134 by year 5 students. For a summary of responses by year group and location see Table 1.

Table 1. Summary of questionnaire responses by year group and location

Group		UK	Malaysia	Total
Year 1	(responses/year group size)	238/300	45/57	283/357
	% year group	79.3%	78.9%	79.2%
Year 3	(responses/year group size)	103/300	11/20	114/320
	% year group	34.3%	55%	35.6%
Year 5	(responses/year group size)	134/300	n/a	134/300
	% year group	44.6%	n/a	44.6%
Total		475	56	531

The preferred nomenclature to describe and individual with a diagnosis of dementia, shared across all groups, was "person with dementia" (57.7%) followed by "person living with dementia" (30.2%). The other terms were rarely selected by students as preferable. Overall, the majority of responses to DCQ statements scored four or five out of five, indicating agreement with DeMEC principles of person-centred communication (Table 2). The only exceptions to this overall confirmatory pattern were DCQ questions 8 and 11. Student response to DCQ 8 and 11 was most often scored three - "neither agree nor disagree", and the range of responses in both cases included all of the Likert categories.[2]

Table 2. Responses to DCQ questionnaire by item

DCQ item *When communicating with people with dementia:*	**Score 1 (%)**	**Score 2 (%)**	**Score 3 (%)**	**Score 4 (%)**	**Score 5 (%)**
1. Older people deserve great respect	0	0.6	11.3	45.3	42.8
2. Conversation can be an important part of their treatment	0	0.9	3.0	52.8	43.2
3. Body language (like gesture and posture) are very important	0	0.6	5.1	47.8	46.5
4. Conversation can be a way of reducing anxiety	0	0.4	5.7	49.1	44.8
5. It is acceptable to touch someone gently to get their attention	0.2	1.5	22.7	60.9	14.7
6. It is helpful if medical or care staff wear uniforms so their professional roles are clear	0.4	3.6	18.4	52.7	24.9
7. Even very confused speech may hold meaning	0.6	2.8	11.9	60.9	23.8
8. **It is acceptable to lie to them if you think the truth might be upsetting to hear**	1.3	17.6	45.0	29.7	6.4
9. You should give them prompts and clues as reminders of who they are or where they are	0	1.1	13.2	61.3	24.3
10. It is important to check with them that they have understood what has been said	0	0.8	4.2	59.0	36.0

[2] The previously submitted book chapter, reporting early findings from the project, includes a statistical comparison of responses between year 1 and year 3 students, and between UK-based students and Malaysia-based students.

11. It is preferable to try to talk to a member of their family first, before speaking to them.	5.1	25.3	38.3	28.4	2.9

Qualitative data

In the first round of qualitative data collection, a total of 21 students contributed to one of 6 focus groups held in the UK and Malaysia. Group size ranged from two to five students. Issues discussed included all aspects of communication covered by the DCQ questionnaire. In the second round of qualitative data analysis, a further 10 students participated in face-to-face (n=6) or telephone (n=4) interviews, concentrating on DCQ questions 8 and 11.

Qualitative data analysis supported the questionnaire findings of general agreement with the majority of DCQ statements, and endorsement of these principles as consistent with person-centred communication. Space does not permit presentation of these confirmative qualitative findings which have been described elsewhere;[3] instead we focus on 2 areas of disagreement and uncertainty - DCQ 8 (It is acceptable to lie to them if you think the truth might be upsetting to hear) and DCQ 11 (It is preferable to try to talk to a member of their family first, before speaking to them).

DCQ 8: "It is acceptable to lie to them if you think the truth might be upsetting to hear". Students believed that honesty should be the default position when communicating with PLWD and their carers, but disagreed as to how honesty should inform action. They agreed that PLWD had an autonomous right to information concerning them, coupled with a professional expectation that doctors should not lie to patients:

[3] As per book chapter referred to above

> Trust is like, important. I think it's different, like, as a doctor, you can't really lie. I mean as a health professional, you've got to tell the truth. (Focus Group 5)

Whilst lying was generally perceived to be unacceptable in clinical practice, students were aware that being open and honest in certain situations risked provoking significant distress for patients - the scenario outlined most frequently was a PLWD asking about the whereabouts of a dead spouse. Under these circumstances, students disagreed as to what would be the most appropriate course of action. Some students expressed a belief that an intention to avoid distress, as a form of harm, could justify lying to a PLWD:

> I suppose you're weighing up what the benefits and the costs are, aren't you? You're, like, it's not really kind of, lying in that situation is not necessarily a bad thing because the overall benefit is good. (Focus group 6)

> Sometimes a white lie will be forgivable, yeah, acceptable. (Focus group 3)

Other students thought that communicative strategies that did not depend on giving false information constituted an acceptable alternative to lying:

> They have a right to hear the upsetting news. And maybe choosing the moment is an important point rather than lying because then that's going to make them even more confused. (Focus Group 5)

Other acts described in order to avoid lying whilst preventing distress included "delaying", "distracting" and "changing the subject". Students were aware of a need to anticipate and

attempt to balance potential outcomes for patients, both positive and negative, of particular communicative practices. Many felt that the most appropriate action depended on complex nuances of each specific clinical scenario, and that there were no definitive rules that could always be followed:

> I think, like you were saying, it's very circumstantial, different with every situation and every person. But I think there has to be an element of using your best judgement for, the person, because I think sometimes it maybe just isn't worth it. (Focus group 4)

Making professional judgements about PLWD was thought to be more complex due to concerns about impaired or fluctuating capacity to understand information:

> how do you judge if the patient is, you know, emotionally or cognitively equipped? You know, and also the other thing is, the patients have good days and bad days so you know, do you decide once a patient is…, that patient isn't equipped, but then they might be equipped on a further day than that, so I don't know to be honest. I think when things are so…, it's hard to decide where the line is, you know it leaves it open to interpretation and again, you know, with all these things, it's very hard to decide. (Interview 9)

Qualitative data from focus groups and interviews provided insight as to why students felt that they neither agreed nor disagreed with DCQ 8 as a statement. Although students expressed a preference to be open and honest with PLWD, and to avoid lying, an absolute rule to never lie was not always thought to be consistent with person-centred care or professional practice. There was considerable diversity as to the rare circumstances under

which students thought that lying might be acceptable, but consensus that each individual case needed to be considered in relation to a balance of potential benefits and harms.

DCQ 11: "It is preferable to try to talk to a member of their family first, before speaking to them". Although the majority of participants agreed that it would be preferable to talk to each individual PLWD before speaking to their family, they were less certain how to go about communication when a person's dementia was advanced. The reason most often given for talking to the PWLD was a need to remain objective and unbiased about that person in the process of developing a therapeutic relationship:

> I mean, it's to start a relationship, it's to get general information, like as much of it as possible, and I think you get that best from the person first hand. (Focus group 4)

Students expressed a concern that speaking to family in advance of a PLWD risked "changing our judgement" or "shaping our mind", and that a PLWD might feel upset or betrayed if their family were approached first. Rather, students believed that talking to family after an initial discussion with a PLWD had a number of potential benefits. They were aware of the caring element often inherent in the relationship between a PLWD and their family, and respectful of the in-depth knowledge and expertise that family members might have about each individual PLWD. In general, students believed that family would have a PLWD "best interests" at heart, and that collaborative information would help support appropriate clinical decision-making.

Matters were thought to be more complex, however, in cases where dementia was advanced, or if a PLWD was reluctant to impart information. Students were aware that, as healthcare

professionals, they may be viewed as a "stranger" by the PLWD, and that it was understandable that a PLWD may not wish to communicate openly with them. In this case, some students thought that it would be appropriate to gather information from family in advance, in order to gain some insight into the preferences and personality of the PLWD, and to tailor their communicative approach. Ultimately, a compromise was often endorsed, where information was sought from different sources simultaneously:

> it's good to talk to them, like briefly, and then talk to the family members, just to get a clue how severe the condition is, and then come back to the patient. (Focus group 2)

As per DCQ 8, qualitative data helped to illustrate why students could neither categorically agree or disagree with DCQ 11 – individual clinical situations concerning PLWD were considered to be too complex to be guided by a hard and fast rule about how information should be obtained. Student highlighted a number of additional factors which might influence their approach to gathering information including the severity of dementia, other medical problems, the nature of the relationship between the PLWD and their family, and the preferences of the PLWD.

Anxieties and uncertainty. Qualitative data collected from focus-groups and interviews highlighted a number of anxieties that students harboured about communicating with PLWD. Students recognised that clinical situations involving PLWD and their families were highly diverse, and that individual circumstances needed to be explored before appropriate decisions could be made. Dementia was generally thought to make communication more challenging:

> I think a lot of students when the first come, you know, into a clinical setting ((I: m-m)), whether it be mental health or otherwise, it's just talking with patients ((I: yeah)), just generally, so when somebody has dementia, it is erm, you know ((I: yeah)), doubly difficult. (Interview 4)

Analysis revealed that communicative engagement with PLWD was fraught with practical, professional and ethical challenges for students, and that they remained uncertain as to how to balance respect for the autonomy of individual PLWD with a concern about causing distress to patients and their families; students were essentially treading a tightrope of gathering and disclosing information congruent with a PLWD's best interests. Many students remarked that it was helpful to come into regular supervised contact with PLWD and their families, in order to witness more senior healthcare professionals communicating with them in different ways:

> I think as you go along you kind of pick up little things ((I: m-m)) that you just don't think are quite right and I think it's good to have an experience of all the good and the bad things you know ((I: m-m)), to see things done well is equally as productive, you know. (Interview 1)

There was a general consensus from students that they had not had as much contact with PLWD and their families, in comparison to patients with other conditions such as heart or lung disease, and that additional experience would be beneficial.

Discussion

Questionnaire, focus group, and interview data revealed a preference for positions which adhered to a person-centred communication approach, but findings relating to the two most

controversial items in the DCQ (truth-telling and interaction with family) highlighted the complexities of applying principles of person-centred communication in the clinical environment. We argue that our data suggests that medical students essentially endorse the principle of person-centredness in care, as outlined by the DeMEC model, while also providing evidence that the principles need further development, both conceptually, in terms of defining their limitations and paradoxes, and in terms of making the model applicable to the clinical environment. Students described a range of specific clinical situations where a person-centred approach necessitated balancing ethical principles, embodied as communicative acts, which were supportive of a PLWD's "best interests".

The uncertainty expressed by students about being able to be completely honest with PLWD at all times is reflected by literature on the ethics of lying and deception in dementia care. Whilst a minority of ethical discourse maintains a deontological view that lying in clinical practice is never acceptable (Bakhurst, 1992; Jackson, 2001), student opinion emerging from this study – that there are rare and specific circumstances where lying might be justifiable is congruent with empirical studies showing that "white lies" and deception do occur in dementia care (Elvish, James & Milne, 2010; Hasselkus, 1997; Hertogh, The, Miesen & Eefsting, 2004; Tuckett, 2012). As per the diversity reflected in this literature as to which circumstances might be justifiable, students were similarly divided in their opinions. Thus, whilst honesty was thought to be a key professional principle to be upheld, the majority of students did not support an absolutist view that lying was never consistent with a person-centred approach.

Similarly, students questioned the practicality of always communicating with a PLWD prior to approaching their family. Whilst students appeared to recognise the need to support the

autonomy of each PLWD by seeking their views and preferences as an individual, and attempting to remain unbiased, they were also aware of the importance of the relationship between a PLWD and their family. This acknowledgement of PLWD existing not necessarily as an isolated individual, but in a social context inherently shaped by their relationship with their family, is reflected by literature on discourse ethics and the ethics of care (Hughes & Baldwin, 2006). Students believed that in many circumstances, person-centred communication involved a dynamic conversation which included family members, rather than an isolated dialogue between themselves and the individual PLWD. This became even more pertinent in cases where advanced dementia was present.

The anxieties expressed by students about the complexity of communicating with PLWD in clinical practice has implications for undergraduate medical education. We advise medical educators to consider integrating person-centred communication skills into undergraduate teaching about dementia. Models such as DeMEC may provide a useful framework, although controversial areas such as lying and deception would need to be further explored and debated, perhaps during ethics and professionalism teaching sessions. A case-base approach, using situations as witnessed by students in practice, is proposed as an appropriate format to stimulate discussion. Further, medical students' person-centred communication skills could be assessed (formatively or summatively) using objective structured clinical examinations (OSCEs) involving simulated scenarios relevant to people living with dementia.

We acknowlegde a number of limitations. The practical difficulties of administering a survey across international sites led to necessary variation in questionnaire administration (paper vs electronic) between groups. As the Malaysian campus did not have year 5 students, year 5 data was limited to the UK. Focus group and interview participants were self-selected and

were therefore likely to have a personal interest in dementia care. This may have introduced bias towards expression of more positive comments and consensus about person-centred communication, but the breadth of responses from participants did raise challenges and concerns about a blanket application of the principles outlined in DeMEC, suggesting that students were not afraid to contradict the model.

Future research could helpfully investigate the extent to which undergraduate students' beliefs and attitudes relating to person-centred communication with PLWD are actually translated into professional behaviour in the clinical context. The UK Department of Health have recently expressed a commitment to improving general education and training for all healthcare professionals (Department of Health, 2014). We suggest that the development and evaluation of targeted education and training for undergraduate and postgraduate healthcare professionals about person-centred communication, as a key component of care, may help to mitigate against the concerns poor communication with PLWD cited above. In the postgraduate environment, communication skills training for old age psychiatrists caring for people with dementia has been shown to have an impact on subjective, self-reported clinical practice (Robinson, Bamford, Briel, Spencer & Whitty, 2009). Further educational research could evaluate the effect of person-centred communication training on healthcare professionals' knowledge, skills and observed behaviours, and ultimately the impact on care of PLWD.

Conclusions

Our research explored the views of medical students regarding application of a model of person-centred communication to the care of PLWD in clinical settings. Students generally endorsed the person-centred approach to communication, but the acceptability or otherwise of

lying, and of communicating with family in advance of the PLWD, were highlighted as complex and divisive issues requiring further exploration through educational research.

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